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ORIGINAL ARTICLE

The hospital provision of reasonable adjustments for people with learning disabilities: Findings from Freedom of Information requests

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Accessible Summary

- The Equality Act 2010 is a law to make sure that people are treated fairly. The law says that anyone providing a service to the general public, including hospitals, must make “reasonable adjustments” for disabled people. A reasonable adjustment is changing the way the hospital usually does things so that disabled people are able to use their services. The aim of this study was to find out whether the funders of health care (called Clinical Commissioning Groups or CCGs) and hospitals were keeping to the Equality Act 2010.
- Some funders and hospitals did not reply to our questions. All of the other funders said that they wrote into their agreements that disabled people must be able to use the hospital. Eight of 186 told us that they checked up on whether this happened or not.
- Most of the hospitals could tell us the number of people with learning disabilities that had been inpatients, but fewer could tell us the number of people with learning disabilities who used outpatients or accident and emergency. About half of the hospitals said they did not check up on services for people with learning disabilities or they did not share these reports with the public.
- This research is important because it suggests that some hospitals may not be following the Equality Act 2010, and that more could be done to make sure that people with learning disabilities are able to access health care.

Abstract

Background: The Equality Act 2010 places a duty on service providers to make “reasonable adjustments” for disabled people. The aim of this study was to explore key aspects relating to the provision of reasonable adjustments for people with learning disabilities in hospitals.

Methods: The research questions were explored using Freedom of Information (FOI) requests submitted to 206 CCGs and 141 hospital trusts in England.

Results: One hundred and eighty-six CCGs reported that they included the requirement to provide equal access to services in their contracts with providers. Eight CCGs provided evidence about how they ensured reasonable adjustments were

provided. One hundred and twelve of 132 responding hospital trusts provided information about the number of inpatients with learning disabilities; eighty-three of 132 provided data about outpatients and 88 of 132 provided data about A&E. Sixty-four of 125 responding trusts explicitly stated that they did not undertake audits of learning disability services or did not make any such reports publicly accessible.

Conclusions: The findings contribute to concern about the gap between legislation and guidance, and its practical application “on the ground.” If CCGs are not assessing contractual compliance to provide equitable access to services for people with learning disabilities, and trusts are not aware of the number of people with learning disabilities using their services, or their access requirements, this raises concerns about their compliance with the Equality Act 2010.

1 | INTRODUCTION

Disabled people¹ in general, and people with learning disabilities in particular, experience many barriers to accessing necessary health care (Alborz, McNally, & Glendinning, 2005; Ali et al., 2013; Dinsmore, 2012; Disability Rights Commission, 2006; Michael, 2008; Sakellariou & Rotarou, 2017; Tuffrey-Wijne et al., 2013, 2014). Sakellariou and Rotarou (2017) summarise key barriers in relation to communication difficulties, lack of health promotion and screening, and inadequate knowledge of doctors about the health needs of people with learning disabilities. They reported that in hospitals, concerns have been identified about the denial of basic needs such as lack of support during meal times or toileting, problems in the administration of medication and inadequate discharge arrangements. Barriers relating to delays in the diagnosis and treatment of illness have been identified as a contributory factor to premature deaths in this population group (Heslop et al., 2013, 2014; Mencap, 2007).

In England, there is a range of legislation, policy and guidance that has a role in ensuring that access to health care is available for people with learning disabilities. Primarily, the Equality Act 2010 enshrines a duty for service providers to make “reasonable adjustments” to ensure that disabled people are not denied access to the same services, as far as this is possible, as someone who is not disabled. There are three key aspects that are covered by the duty to provide reasonable adjustments for disabled people:

- Changing a practice, policy or procedure that makes it more difficult for disabled people to access or use services.
- Changing a physical feature to remove, change or provide a reasonable way of avoiding barriers such as steps, doors, toilets or signage.

- Providing extra aids or services where it would help disabled people, such as using British Sign Language interpreters, or providing information in an alternative format (Equality Act 2010, S20).

In addition, the Health and Social Care Act 2012 places the legal obligation on NHS England, and Clinical Commissioning Groups (CCGs), to reduce inequalities in access to health and health outcomes (Health and Social Care Act 2012, S13G, S14T). NHS England is required to assess its own compliance to the Act, and that of CCGs, and to publish an annual report which assesses how effectively both it and CCGs have discharged their duties (NHS England, 2017).

In addition, the independent regulator of health and social care services in England, the Care Quality Commission (CQC), monitors and inspects NHS and independent hospitals, to make sure they meet fundamental standards of quality and safety. One of the key lines of enquiry for the CQC is whether the service is responsive to people's needs, and this includes assessing whether reasonable adjustments, as defined and required by legislation, are made so that disabled people can access and use services on an equal basis to others (Care Quality Commission, 2017). In their analysis of CQC inspection reports for 30 acute NHS trusts published in 2016, Baines and Hatton (2018) concluded that most reports routinely contained some information about how well hospitals were working for people with learning disabilities and that most of these comments were positive. They found that in general, the proportion of negative comments increased as the CQC rating for how well the trust was performing became less positive, but the depth of information in reports varied across trusts.

The main questions the CQC has asked in its inspections since 2016 were designed to reflect the six criteria set by Monitor² prior to its incorporation into NHS Improvement³ in 2016, about the

¹In the United Kingdom, according to the social model of disability, “disability” is not a description of a personal characteristic. A disabled person is not a “person with a disability” as the person does not own the disability. The term “disabled person” is used in this manuscript in line with the Disability Rights Movement which recognises disability as social oppression—something external to the person. Significantly, this terminology also acknowledges something that can be changed.

²Monitor was the sector regulator for health services in England from 2004 until its incorporation into NHS Improvement in 2016.

³NHS Improvement supports foundation trusts and NHS trusts to provide consistently safe, high quality, compassionate care to patients, within local health systems that are financially sustainable.

extent to which health services met the health needs of people with learning disabilities (Tables 1 and 2). Of the former Monitor criteria, two were particularly pertinent to the provision of reasonable adjustments: Whether the trust could identify and flag patients with learning disabilities and ensure reasonably adjusted care, and whether the trust had protocols in place to audit its practices for patients with learning disabilities and to demonstrate the findings in routine public reports.

In December 2014, whilst the Monitor criteria were still operational, Mr. Tom Clarke Labour Party MP, asked a question in Parliament about the compliance of NHS foundation trusts to the criteria relating to meeting the health needs of people with learning disabilities. The response provided by the Parliamentary Under-Secretary for the Department of Health was that all NHS foundation trusts reported full compliance with the six Monitor criteria (UK Parliament, 2015). More recent data published in the findings of the 2015 Joint Health and Social Care Self-Assessment Framework (Public Health England, 2015) suggested that local areas were rather less confident: 49% ($n = 74$) of localities completing the assessment rated themselves as "green" indicating full compliance; 38% ($n = 57$) rated themselves as "amber" and 5% ($n = 8$) as "red." A further 9% ($n = 13$) provided no response to the question.

Other than this self-reported confirmation, there has been little research or investigative evidence that has confirmed this compliance with the Monitor criteria up to 2016, or the CQC questioning from 2016 onwards. Glover, Fox, and Hatton (2016) reported findings from a survey of Learning Disability Partnership Boards⁴ in England who were asked to report the numbers of hospital admissions, outpatient, and accident and emergency (A&E) attendances involving people with learning disabilities during the previous year at the hospitals serving their local areas. The rationale for the question was to determine whether hospitals were identifying people with learning disabilities, as a precursor to making appropriate reasonable adjustments. Glover et al. (2016) reported that 41% of Partnership Boards did not provide usable data for inpatient care, 55% for outpatients and 55% for A&E attendances. An additional 30% of Partnership Boards supplied some data, but the authors reported that these were either incomplete or evidently inaccurate. They concluded that approximately a half of healthcare commissioners may not be actively monitoring the extent to which hospitals identified and made reasonable adjustments for people with learning disabilities.

Hatton, Roberts, and Baines (2011) conducted a national survey of NHS trusts in Autumn 2010 to map the extent and nature of reasonable adjustments they were making for people with learning disabilities in England. Data from the 119 trusts that responded to the survey indicated that "only a minority of responding trusts could provide us with specific information about people with learning

TABLE 1 Monitor criteria for access to services for people with learning disabilities, until 2016

Does the trust have a mechanism to identify and flag patients with learning disabilities and protocols that ensure pathways of care are reasonably adjusted to meet the health needs of these patients?
Does the trust provide readily available and comprehensible information to patients with learning disabilities about the following criteria: treatment options; complaints procedures; appointments?
Does the trust have protocols to provide suitable support for family carers who support patients with learning disabilities?
Does the trust have protocols to routinely include training on providing healthcare to patients with learning disabilities for all staff?
Does the trust have protocols to encourage representation of people with learning disabilities and their family carers?
Does the trust have protocols to regularly audit its practices for patients with learning disabilities and to demonstrate the findings in routine public reports?

Note. Monitor (2015).

TABLE 2 Questions CQC inspectors are asked to cover on inspections since 2016

Whether the hospital knows who the people in the hospital with learning disabilities are
What reasonable adjustments they can and do make for people with learning disabilities
Whether they have a specialist nurse for learning disabilities
Whether they audit the care given to patients with learning disabilities

Note. Department of Health (2014). p. 4

disabilities using the trust, for example in terms of the number of patients with learning disabilities who had used the trust's services" (p. 8).

1.1 | Research questions

The aim of this study was to explore key aspects relating to the provision of reasonable adjustments for people with learning disabilities, specifically the contract requirements on providers, and the extent to which hospitals identify and make reasonable adjustments for people with learning disabilities. Our specific research questions were as follows:

1. To what extent do CCGs refer to the provision of reasonable adjustments for patients with learning disabilities in their contracts with providers?
2. What proportion of hospital trusts can provide data about the numbers of patients with learning disabilities attending inpatient, outpatient or A&E departments?
3. What proportion of hospital trusts provides publicly accessible reports about audits of its practices for patients with learning disabilities?

⁴Learning Disability Partnership Boards are multiagency fora, also including people with learning disabilities and their families. They act as a catalyst for interagency working to improve the quality of life and promote choices and control for people with learning disabilities.

2 | METHODS

The research questions were explored using Freedom of Information (FOI) requests submitted in 2016.

The Freedom of Information Act 2000 created a general “right of access” to information held by public authorities. Under the Act, any person making a request for information to a public authority is entitled to be informed in writing by the public authority whether it holds the information requested, and if that is the case, to have that information communicated to them within 20 working days (Freedom of Information Act, S1). The Act recognises that some kinds of information may be withheld, such as if its release would prejudice national security, damage commercial interests or if the public interest in withholding the information outweighs the public interest in releasing it. In addition, public authorities are not obliged to report data if the cost would exceed £450 (known as a Section 12 exemption), or if they consider the information requested is already reasonably accessible to the applicant by other means (Section 21 exemption). If the authority decides that the information cannot be released, it must inform the person requesting the information, and explain why.

2.1 | FOI request to clinical commissioning groups

In February 2016, we sent a FOI request to all 206 CCGs in England in existence at the time of the request. The FOI request asked a single question:

What is the exact wording contained in your contracts with providers to ensure the provision of reasonable adjustments for people with learning disabilities is embedded in practice?

To support this question, we outlined the legal basis for the provision of reasonable adjustments that is included in the UK Equality Act 2010 and provided clarification about the term “learning disabilities,” employing that described in “Valuing People,” the Learning Disability White Paper (Department of Health, 2001).

2.2 | FOI request to hospital trusts

In February 2016, we also sent a FOI request to all 89 NHS foundation trusts and 52 NHS trusts (Figure 1) in England that met two inclusion criteria: First, the trust had to provide inpatient, outpatient and A&E services; the second related to the size of the trust—the total inpatient admissions, and attendances at outpatients and A&E had to exceed 1/1,000 of the total England rate for each service.

Trusts were asked two questions as part of the FOI request. First, we requested the total number of people who were admitted to, or attended, their inpatient, outpatient and A&E departments in the 2014–15 administrative year, and the total number of patients with learning disabilities accessing each of these services. Second, we requested that the trust provides us with information about how to locate publicly accessible reports documenting the findings of audits into the provision of services for people with learning disabilities.

For both FOI questions to trusts, we made an overt reference to the respective Monitor criteria in operation at the time (i.e., Monitor 2015: criterion 1 and 6, p. 57). Although the Monitor criteria were specific to NHS foundation trusts at that time, we reasoned that the questions were also relevant in assessing the CQC key line of enquiry about responsiveness of services (Care Quality Commission, 2017). These criteria were that trusts should be able to identify patients with learning disabilities, and audit the provision of care to them.

Nonresponding CCGs and trusts were followed up by the research team. If they did not respond to a second request, no further action was taken.

3 | RESULTS

3.1 | FOI request to clinical commissioning groups

Responses were received from 186 (90%) CCGs. Twenty CCGs (10%) did not respond to the request, despite a reminder being sent. These CCGs have been excluded from the following analyses.

NHS foundation trusts were introduced by the Health and Social Care (Community Health and Standards) Act 2003. They differ from mainstream NHS trusts in a number of ways:

- They have greater freedom to decide how to meet local health obligations
- They are intended to be more directly accountable to local people
- They are authorised and regulated by a separate Independent Regulator of NHS Foundation Trusts - Monitor - which was established in January 2004.

In all other respects, NHS foundation trusts have the same responsibilities as NHS trusts.

FIGURE 1 NHS foundation trusts, and NHS trusts

Of the 186 CCGs that did respond to the FOI request, the majority (88%; $n = 163$) referenced, or provided an extract from, SC13 of the 2015/16 NHS Standard Contract (NHS England, 2016) which relates to equity of access, equality and nondiscrimination. This states the following:

13.1 The Parties must not discriminate between or against service users, carers or legal guardians on the grounds of age, disability, marriage or civil partnership, pregnancy or maternity, race, religion or belief, sex, sexual orientation, gender reassignment, or any other non-medical characteristics,⁵ except as permitted by the Law.

13.2 The Provider must provide appropriate assistance and make reasonable adjustments for service users, carers and legal guardians who do not speak, read or write English or who have communication difficulties (including hearing, oral or learning impairments). The Provider must carry out an annual audit of its compliance with this obligation and must demonstrate at review meetings the extent to which service improvements have been made as a result. (NHS England 2016, S13).

The remaining 23 CCGs provided examples of alternative contracts with providers. For example, several CCGs reported that contracts for specific services such as Community Learning Disability Teams included the requirement to

support generic health care providers to make reasonable adjustments to ensure good health outcomes for people who have learning disabilities

or to

support mainstream community services and primary care to undertake reasonable adjustments in order to support effective treatment.

Other areas reported contractual requirements across a range of providers, for example one CCG reported that their contracts included the requirement to

foster a culture in which everyone understands reasonable adjustments and how they can help everyone when applied in a timely and appropriate manner

another required providers to “apply reasonable adjustments for all disabilities and impairments and across all functions”.

Eight CCGs provided evidence about how they ensured reasonable adjustments were embedded in practice through their contracts with providers. Most of these specified audit and quality assurance checks as a way of ensuring the provision of reasonable adjustments: for example, one CCG required providers to “carry out an annual audit,” and another required that a “quarterly audit [is] undertaken in a minimum of five community services to ensure adherence to protocol and to provide evidence on an annual basis.” In their response to the FOI request, one CCG commented as follows:

It is more likely that commissioner quality teams will pick up issues via site visits and feedback via Clinical Quality Review Groups, the result of which could be that issues are addressed via the performance management clauses in the contract.

3.2 | FOI request to hospital trusts

Eighty-five of the 89 NHS foundation trusts (96%) and 47 of the 52 NHS trusts (90%) provided a response to the FOI request. The remaining trusts provided no information at all (three NHS foundation trusts and five NHS trusts); these trusts have been excluded from the following analyses.

Table 3 shows the number and proportion of NHS foundation and NHS trusts that provided data about patients with learning disabilities in inpatient, outpatient or A&E departments in the specified time period.

As Table 3 shows, most trusts (87% of NHS foundation trusts and 81% of NHS trusts) provided information about the number of inpatients with learning disabilities. Fewer were able to provide data about people with learning disabilities using outpatients (68% of NHS foundation trusts and 53% of NHS trusts), or A&E (67% of NHS foundation trusts and 66% of NHS trusts), but overall, 60% of NHS foundation trusts and 53% of NHS trusts were able to provide data about all three services.

However, there was a substantial minority of trusts that were unable to provide the requested data about people with learning disabilities. Several specified a Section 12 exemption on the grounds of cost, most commonly because “the information you require is not routinely monitored or recorded on our system” (NHS Foundation trust) or “Regrettably we are not able to identify patients with learning disabilities through our datasets” (NHS trust). Similarly, trusts that were unable to provide the data requested most commonly reported that they “do not have a way to identify patients with learning disabilities” (NHS Foundation trust) or that the trust “does not actively flag patients with learning disabilities” (NHS trust).

It is doubtful whether the data provided by some trusts are accurate, for example one NHS Foundation trust reported that just 12 patients with learning disabilities accessed inpatient, outpatient and A&E services over the course of a year, and another noted that the data were captured via a risk flag or alert recorded in the patient's notes, so it “cannot be relied upon to be accurate.” In addition, many trusts provided the number of attendances or episodes of care by

⁵The Equality Act 2010 covers the same groups that were protected by previous equality legislation—age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership and pregnancy and maternity. These are now called “protected characteristics.”

NHS foundation trusts (n = 85)	Inpatient		Outpatient		Accident and emergency		All three settings	
	n	% ^a	n	% ^a	n	% ^a	n	% ^b
Provided data about patients with learning disabilities	74	87%	58	68%	57	67%	51	60%
Did not provide data requested	6	7%	18	21%	21	25%	5	6%
Section 12 exemption	5	6%	9	11%	7	8%	4	5%
NHS Trusts (n = 47)								
Provided data about patients with learning disabilities	38	81%	25	53%	31	66%	25	53%
Did not provide data requested	7	15%	19	40%	14	30%	7	15%
Section 12 exemption	2	4%	3	6%	2	4%	2	4%
Total (NHS foundation and NHS trusts; n = 132)								
Provided data about patients with learning disabilities	112	85%	83	63%	88	67%	76	58%
Did not provide data requested	13	10%	37	28%	35	27%	13	10%
Section 12 exemption	7	5%	12	9%	9	7%	5	4%

Note. ^aMay not total 100% due to rounding. ^bDoes not total 100% as data is for all three settings.

TABLE 3 NHS foundation and NHS trusts response to FOI request about number of patients with learning disabilities in inpatient, outpatient or A&E departments in the specified time period

Availability of audit information	NHS foundation trust (n = 81)		NHS trust (n = 44)		NHS foundation and NHS trusts (n = 125)	
	n	% ^a	n	% ^a	n	% ^a
Trust provided sufficient information to allow us to locate relevant audit material	24	30%	8	18%	32	26%
Trust provided insufficient information to allow us to locate relevant audit reports	17	21%	12	27%	29	23%
Trust reported that they did not undertake or publish relevant audit reports	40	49%	24	55%	64	51%

Note. ^aMay not total 100% due to rounding.

TABLE 4 The availability of audit information by trusts in relation to services for people with learning disabilities

people with learning disabilities, rather than the number of people with learning disabilities accessing care.

Eighty-one of the 85 NHS foundation trusts and 44 of the 47 NHS trusts provided some information in response to the second part of our FOI request about where we could find publicly accessible reports documenting the findings of audits into the provision of services for people with learning disabilities. Table 4 shows the availability of audit information by trusts in relation to services for people with learning disabilities.

As Table 4 shows, 30% of NHS foundation trusts and 18% of NHS trusts provided sufficient information to allow publicly accessible relevant audit information to be located and viewed. These trusts generally provided a direct link to Board Papers, Quality Accounts reports, Equality information reports, patient experience reports or specific learning disability reports that were available on their website; some trusts provided more general web links, sufficient to allow relevant audit reports to be located after searching. We did not assess the quality of audit reports relating to services for people

with learning disabilities, merely whether relevant audit information was publicly available. However, six of the 24 (25%) NHS foundation trusts and four of the eight (50%) NHS trusts that provided audit data were unable to also provide the number of people with learning disabilities accessing inpatient, outpatient and A&E services.

Approximately a quarter of trusts (21% of NHS foundation trusts and 27% of NHS trusts) did not provide sufficient information to allow publicly accessible relevant audit information to be located and viewed. This included trusts that provided a specific link to documentation that was irrelevant to the FOI request, such as safeguarding reports that did not clearly include reference audit information about services for people with learning disabilities, or trust web pages about services for people with learning disabilities that gave no indication about any audit or evaluations of services.

Approximately a half of trusts (49% of NHS foundation trusts and 54% of NHS trusts) explicitly stated that they did not undertake audits of learning disability services or did not make any such reports publicly accessible. Most commonly, trusts simply stated "The trust has not undertaken any specific audits for patients with learning disabilities" (NHS Foundation trust), "The trust has not published any audits or reports" (NHS Foundation trust) or "The trust does not have this information" (NHS Foundation trust). A few trusts identified current work in this area, for example one NHS Foundation trust wrote

We are currently undertaking a series of audits on our care for patients flagged with learning disabilities as part of a CQUIN⁶

agreed with our local CCG. It would be our intention to publish the results of those audits at the end of the year

and another NHS Foundation trust noted as follows:

We are in discussion with the trust's audit team, carrying out a joint audit with the community health trust around practices and care delivery and patient carer satisfaction, for patients with a learning disability who use the acute services.

4 | DISCUSSION

The aim of this study was to explore key aspects of the provision of healthcare-related reasonable adjustments for people with learning disabilities, specifically in relation to contract requirements on providers, and the extent to which hospitals identify and make reasonable adjustments for people with learning disabilities. The

information was obtained through FOI requests to CCGs and hospital trusts in England.

We found that all CCGs that responded to our FOI request required the provision of reasonable adjustments for disabled people in their contracts with providers, most commonly through the use of the NHS Standard Contract (see NHS England, 2016). Only eight CCGs provided evidence about how they ensured reasonable adjustments were embedded in practice through their contracts with providers. The majority of hospital trusts that responded to our FOI request provided information about the number of inpatients with learning disabilities, but fewer were able to provide data about people with learning disabilities using outpatients or A&E, and only 60% of NHS foundation trusts and 50% of NHS trusts were able to provide data about all three services. Fewer than a third of trusts provided sufficient information to allow publicly accessible relevant audit information to be located and viewed; approximately a half of trusts explicitly stated that they did not undertake audits of learning disability services or did not make any such reports publicly accessible.

There are a number of potential limitations of the study which need to be acknowledged. Twenty CCGs, four NHS foundation trusts and five NHS trusts did not respond to the FOI request, despite this being a legal requirement. It may have been that the FOI request was misdirected, although all public authorities are required to explain how they deal with requests for information under the Freedom of Information Act and provide contact details to make it easier for applicants to submit requests or seek assistance (Freedom of Information Act 2000, S.45). Several trusts gave a Section 12 exemption, indicating that the information was not routinely available and would be too expensive to provide, and a notable minority were unable to provide the information requested, particularly the number of patients with learning disabilities attending outpatients or A&E. Verification of the accuracy of the data was not undertaken, but some entries were reported to be of doubtful accuracy, or evidently appeared to be so. We did not assess the quality of audit reports relating to services for people with learning disabilities, merely whether relevant audit information was publicly available. However, that a trust was able to provide relevant audit information did not also necessarily mean that they could also provide the number of people with learning disabilities accessing inpatient, outpatient and A&E services.

The FOI requests were sent in early 2016, just before Monitor became a part of NHS Improvement. A subsequent report from the Equality and Human Rights Commission (2017) identified concerns in relation to disabled people in general in the United Kingdom, noting that the NHS and Public Health Outcomes Frameworks should enable disaggregation of outcome data by whether a person was disabled. They concluded that there are "very limited data" being collected about outcomes for disabled people, making it

very difficult for the UK Government, Clinical Commissioning Groups and NHS trusts to assess the

⁶CQUIN refers to Commissioning for Quality and Innovation (CQUIN) national goals. CQUINs were introduced in 2009 to make a proportion of healthcare providers' income conditional on demonstrating improvements in quality and innovation in specified areas of patient care.

extent of inequalities experienced by disabled people generally, and disabled people with specific impairments, in access to, experience of, and outcomes from NHS provision at both a national and a local level (p. 77).

The study does highlight a number of important points for consideration. All responding CCGs reported that they issued a contractual requirement for providers to ensure equal access to their services for disabled people, and to provide reasonable adjustments as required, but few actively assessed this and thus, presumably, would be unable to provide assurance about their compliance with the Equality Act 2010. This echoes the findings of Hatton et al. (2011) who reported that few trusts “provided robust evidence to support their statements” about their provision of reasonable adjustments for people with learning disabilities (p. 8). In addition, it appears that many trusts in our study were unable to identify people with learning disabilities as a separate subgroup, and as such would be unlikely to be able to identify and record which of these patients required reasonable adjustments and whether such provision was made. This extends Glover et al.’s (2016) study of Learning Disability Partnership Boards in England and suggests that Partnership Boards may not have known the number of people with learning disabilities who access hospital services because many trusts themselves do not collect this data.

The continuing gap between legislation and guidance and its practical application “on the ground” is of concern. Tuffrey-Wijne et al. (2014) proposed that the failure to identify this patient population may be due to several factors, including patient record systems not being integrated with those of other NHS services, including primary care; a lack of effective flagging systems within the hospitals; a lack of staff knowledge and skill in identifying that a person may have learning disabilities; and staff reluctance to record the presence of learning disabilities because of a fear of ascribing a “negative label” on people. Tuffrey-Wijne et al. (2013) noted that despite sometimes having “the right” (p. 9) policies in place, it was the response of individual staff members, the leadership and culture of the ward, and the resources available to staff that were more important in terms of whether reasonable adjustments were provided.

The House of Lords Select Committee review of the Equality Act in relation to disabled people identified a more fundamental failure and concluded that the provisions of the Act were “neither well-known nor well understood” (House of Lords, 2017, p. 62) by both service providers and disabled people. They called for the Equality and Human Rights Commission to prepare a specific Code of Practice on the provision of reasonable adjustments that could help service providers and disabled people to have a fuller understanding of what compliance to the Act entails. Without this, they warned, there remains the risk of service providers acting illegally because of ignorance of their obligations.

The Monitor Risk Assessment Framework is no longer in operation, and some initiatives are underway to address the apparent disparity between policy and practice. NHS Improvement is currently working with a range of stakeholders to develop a new framework of learning disability improvement standards for all

trusts. Evidence of compliance against the standards will provide trusts with important assurances that they have the prerequisite infrastructure for improvement, as they continue to develop their services. Amongst the standards, one relates specifically to improving equity through reasonable adjustments. Specific improvement measures required to ensure NHS trusts are meeting this standard include an ability to provide transparent evidence of wide-ranging reasonable adjustments being made, to ensure equality of outcome. Also, trusts should have a mechanism in place to identify and “flag” patients eligible for reasonable adjustments, and record the reasonable adjustments they require, from the point of admission through to discharge; and to share this information with others involved in the person’s care.

The Standards will be supplemented by an improvement toolkit which is also in development. This will use ratings from multiple informants (ranging from board members to people who use services), to determine a reliable consensus as to how well trusts are meeting the needs of people with learning disabilities, their families and carers; and to plan actions to deliver improvements.

The extent to which the English NHS Improvement provider standards will be delivered and the use of the associated toolkit is of interest. The expectation is that the standards will be used to determine the level and type of support that the trust receives from NHS Improvement. Those NHS trusts who are fully compliant with the standards would be given maximum autonomy, including fewer data and monitoring requirements and endorsement of their work; conversely, at the opposite end of the spectrum, those in “special measures,” or where there are serious concerns about lack of compliance with the new standards, would be provided with more direct and tailored support to help stabilise and improve their performance.

In addition, NHS England and Mencap have recently undertaken focused work on encouraging people with learning disabilities to be included on their GP learning disability register (see: <https://www.mencap.org.uk/advice-and-support/health/dont-miss-out>). They have also been encouraging people to ask their GP practice for additional information about their need for reasonable adjustments to be added to their summary care record (SCR). The SCR is an electronic patient record containing up to date key information from the patient’s GP record. NHS England has requested NHS Digital⁷ investigate the delivery of a nationally available “flag” for patients, accessible by NHS staff directly involved in the care of the patient through the SCR. The “flag” would identify the following: If a patient has been identified by a care provider as being potentially eligible for reasonable adjustments as defined within the Equality Act 2010, and any reasonable adjustments to care that should be considered, when providing care for that patient (Mullaney & Jeeves, undated). While this may go some way to identifying people with learning disabilities who may need reasonable adjustments, the issue remains for hospitals about how they can be sure that such adjustments are being provided and their effectiveness evaluated.

⁷NHS Digital is the national information and technology agency that supports the health and social care system in England.

The focus of our study was whether CCGs and hospital trusts are aware of disabled people using their services, and whether they audit the provision of reasonable adjustments. We did not inquire about actual adjustments made because what may be reasonable in one set of circumstances may not be so in another. Factors which may be considered when assessing if an adjustment is reasonable or not include how practicable it is to make the adjustment, the financial and other costs involved and their impact of the service provider, and whether the adjustment will address the disadvantage faced by one or more disabled people. However, we know that many hospitals are developing innovative, creative and person-centred ways of delivering reasonable adjustments for people with learning disabilities. These have been evidenced at recent workshops run by the project known as "Getting Things Changed" at University of Bristol (see: <http://www.bristol.ac.uk/sps/gettingthingschanged/>). Nationally, Public Health England and the National Development team for Inclusion have a resource bank about making reasonable adjustments for people with learning disabilities which is archived at: <http://webarchive.nationalarchives.gov.uk/20160704153207/https://www.improvinghealthandlives.org.uk/adjustments/>. A more recent collection of guides about making reasonable adjustments for patients is at: <https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities>.

These can, and do, act as an incentive for practitioners to think about what may be possible, and to share how they responded to such needs. However, the findings of our FOI requests suggest that it is likely that CCGs and hospital trusts still have some way to go before they can be assured that they are meeting the requirements of the Equality Act 2010, and the Health and Social Care Act 2012, with regard to the provision of reasonable adjustments for people with learning disabilities.

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